



# Partners Meeting

## 2/13/03

Gilberto F. Chávez, MD, MPH  
Director, Division of Birth Defects and  
Developmental Disabilities

Centers for Disease Control and Prevention

National Center on Birth Defects  
and Developmental Disabilities



**SAFER • HEALTHIER • PEOPLE™**

# In the Past 12 Months

- Over 4 million infants were born in the US
  - Over 120,000 with birth defects
  - Thousands of infants died due to birth defects
- 1 in 5 children under 18 lived with a developmental disability
  - Thousands were newly diagnosed
- The lives of millions of American families were greatly impacted by birth defects and developmental disabilities
- The resulting costs to the health care and educational systems were staggering



**SAFER • HEALTHIER • PEOPLE™**

# What do we do in the DBDDD?

- We develop and support state of the art birth defects and developmental disabilities surveillance systems.
- We conduct etiologic research to identify the causes and risk factors for birth defects and developmental disabilities.
- We develop well-evaluated and replicable prevention programs for the known causes of birth defects and developmental disabilities.



**SAFER • HEALTHIER • PEOPLE™**

# **Our work in the DBDDD is extremely important because we ...**

- Identify the causes of Birth Defects and Developmental Disabilities
- Develop science-based well evaluated and replicable public health programs
- Aim at preventing birth defects and developmental disabilities



**SAFER • HEALTHIER • PEOPLE™**

# **Our work in the DBDDD is extremely important because we ...**

- Lessen morbidity and save lives
- Make a tremendous difference in the lives of people in the US and around the globe
- Work to support families, providers, and communities
- Are a vital component of the public health system

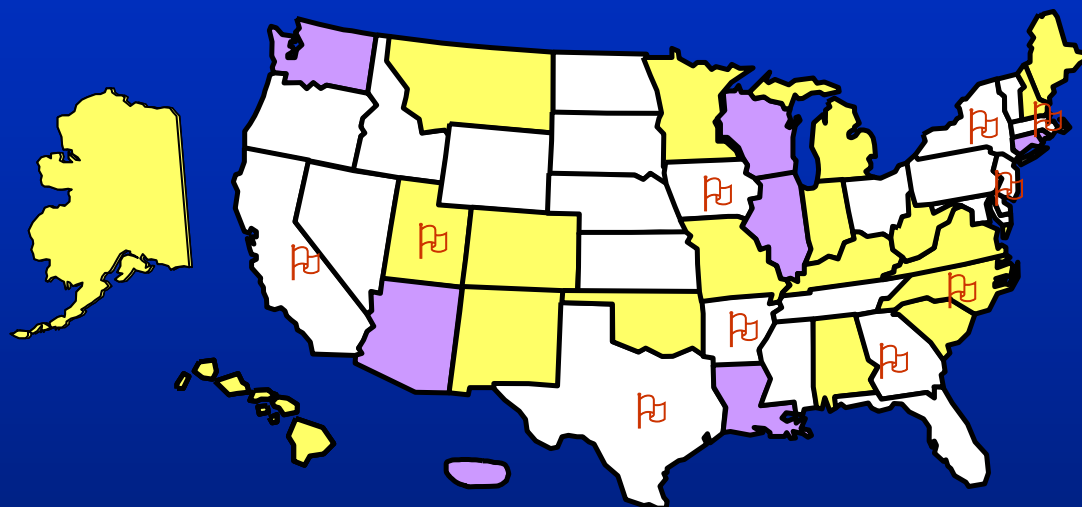


**SAFER • HEALTHIER • PEOPLE™**

# Update of Recent Activities

## Birth Defects

### Cooperative Agreements for BD Activities



 Centers for Birth Defects Research & Prevention

Arkansas  
California  
CDC  
Iowa  
Massachusetts  
New Jersey  
New York  
North Carolina  
Texas  
Utah

#### 2000 Awardees

Arizona  
Connecticut  
Illinois  
Louisiana  
Puerto Rico  
Rhode Island  
Washington  
Wisconsin

#### 2002 Awardees

Alabama  
Alaska  
Colorado  
Hawaii  
Indiana  
Kentucky  
Maine  
Michigan  
Missouri  
Minnesota  
Montana  
New Hampshire  
New Mexico  
North Carolina  
Oklahoma  
South Carolina  
Utah  
Virginia  
West Virginia  
District of Columbia



**SAFER • HEALTHIER • PEOPLE™**

# **Birth Defects Cooperative Agreements — Accomplishments**

- 35 operational programs, 10 planning programs
- Improved in timely and quality of birth defects data, specifically NTDs (18)
- Initiated/fine-tuned prenatal surveillance (7)
- Initiated activities to assist families with NTD-affected pregnancies (14)
- Formed multi-agency collaborations to carry out prevention and intervention projects (18)
- Established a system to referral children to services/follow-up to access to care (10)



**SAFER • HEALTHIER • PEOPLE™**

# **Future Cooperative Agreements for Birth Defects Surveillance**

- RFA will be released within the next two weeks
- New awards expected for September 2003
- 8-12 state programs
- Focus: use of data for intervention and prevention as well as evaluation of those activities
- New emphasis on collaboration with state, local, and tribal MCH programs
- CDC will continue to provide technical support



**SAFER • HEALTHIER • PEOPLE™**





# **The National Birth Defects Prevention Study: What's New?**

Centers for Disease Control and Prevention

National Center on Birth Defects  
and Developmental Disabilities



**SAFER • HEALTHIER • PEOPLE™**

# Importance of the National Birth Defects Prevention Study

- Unique opportunity to study both common and rare defects
- Geographically and ethnically diverse population
- Unprecedented capacity to explore gene-environment interactions
- Model for the study of other outcomes, e.g., developmental disabilities



**SAFER • HEALTHIER • PEOPLE™**

# **National Birth Defects Prevention Study**

## **– Recent Accomplishments**

- Completed over 12,620 interviews for a recent participation rate of approximately 75%
- Developing a comprehensive research agenda with over 100 projects proposed to date
- Released a completely coded and cleaned dataset containing
- Developed sophisticated tools to assist in the appropriate analysis of the data
- Awarded cooperative agreements to 2 new Centers
- Established a centralized lab for genetic material processing



**SAFER • HEALTHIER • PEOPLE™**

# National Birth Defects Prevention Network



- Over 225 members from 50 states, DC, Puerto Rico, and several countries
- Established in 1997; Incorporated in 2000
- Objectives:
  - Improve quality of surveillance data
  - Promote scientific collaboration
  - Provide technical assistance for data collection
  - Facilitate the dissemination of information
  - Compile and make available state surveillance data
  - Use birth defect data for health services planning



**SAFER • HEALTHIER • PEOPLE™**

# National Birth Defects Prevention Network



- Published in *Teratology* the 2002 Congenital Malformations Surveillance Report, a state-based surveillance report with birth defects data from 31 states, 11 scientific articles, and a directory of all state birth defects programs.
- Developed and maintained a web site for state-based surveillance information, queryable birth defects data, Network news, and links to state birth defects programs.
- Published in *Teratology* a paper, “Prevalence of Spina Bifida and Anencephaly during Optional and Mandatory Folic Acid Fortification in the United States,” with data from 26 population-based surveillance systems.



**SAFER • HEALTHIER • PEOPLE™**

# Selected Birth Defects Activities

- Collaboration with China
- Congenital heart defects epidemiology
- Studying increasing rates of gastroschisis
- Survival and prognostic factors for children with Down's syndrome
- Air pollution and birth defects
- Small area analysis of birth defects rates
- Contribution of 22q11del to orofacial clefts
- Linkage of MACDP data with Children 1st data
- Trends in diabetes and birth defects



# Developmental Disabilities

- Cause 12% of school age children to need special education
- Cost over \$36 billion for special education
- Most causes unknown



**SAFER • HEALTHIER • PEOPLE™**

# **Developmental Disabilities Activities: Metropolitan Atlanta Developmental Disabilities Program**

- Initiated sixth year (2000) of surveillance data collection
- Published an article on the prevalence of autism in Metropolitan Atlanta
- Conducting an autism validation study
- Working with partners and the Federal Department of Education to obtain umbrella FERPA exception for public health surveillance activities

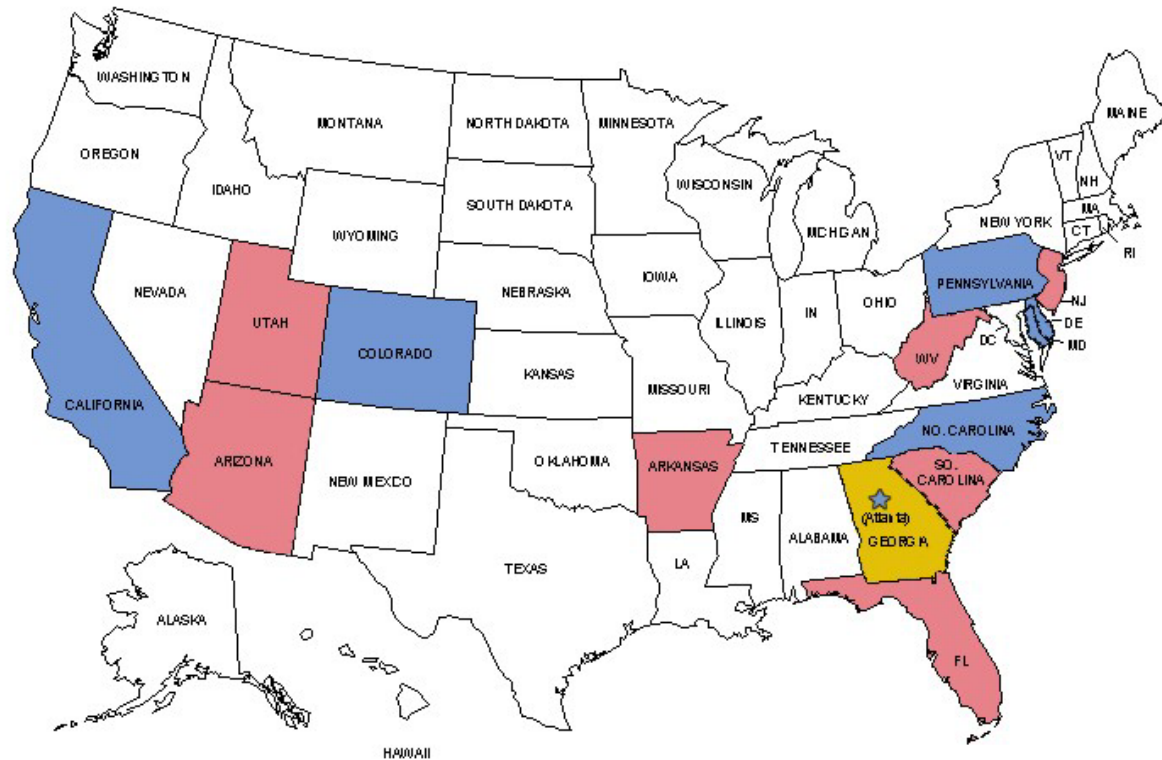


**SAFER • HEALTHIER • PEOPLE™**



# Expansion of State-Based Autism Activities Supported by CDC

State Autism Monitoring and Research Activities



Autism and Developmental Disabilities  
Monitoring (ADDM) Network

Centers for Autism and Developmental  
Disabilities Research and Epidemiology  
(CADDRE)

CDC

ADDM Network:

7 programs + CDC

CADDRE:

5 programs + CDC



**SAFER • HEALTHIER • PEOPLE™**

# Autism and Developmental Disabilities Monitoring Network

- Funded three additional ADDM states (Arkansas, Florida and Utah) starting FY 2003
- Obtained institutional approval at the majority of data collection sources
- Implemented use of Microsoft Access-based electronic abstraction instrument
- Held training sessions at CDC for ADDM state data abstractors and project coordinators
- Initiated data collection at non-school sources for the 2000 Study Year
- Continued to address roadblocks in accessing education records



**SAFER • HEALTHIER • PEOPLE™**

# Autism Research and Epidemiology

- Centers for Autism Research and Epidemiology
- CDC-Danish Collaborative Studies
- Metropolitan Atlanta Study of descriptive epidemiology of autism
- Metropolitan Atlanta Study of MMR vaccine and autism
- Preventing Secondary Conditions Of Autism: Marshall University



**SAFER • HEALTHIER • PEOPLE™**

# **Centers Of Excellence For Autism And Developmental Disabilities Research And Epidemiology**

- In 2002 CDC funded 1 additional Center in North Carolina
- Increasing the geographic areas in which systematic monitoring of autism will be conducted
- Increasing the size of the total population thus enhancing the ability of collaborative epidemiological studies to identify autism risk factors



**SAFER • HEALTHIER • PEOPLE™**

# **Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology**

- Structure for study, case ascertainment methods and priority areas of study identified
- Development of research agenda
- IRB approval for several investigator-initiated studies



**SAFER • HEALTHIER • PEOPLE™**

# Kernicterus In Full-Term Infants

- Increased public health awareness of the problem
- Participated in Making Advances Against Jaundice in Infant Care (MAJIC) Steering Committee Meeting
- Awarded 2 cooperative agreements for research and prevention of kernicterus
  - Pennsylvania Hospital in collaboration with Parents and Infants of Children with Kernicterus (PICK)
  - Saint Peter's University Hospital, NMDNJ-Robert Wood Johnson Medical School.



**SAFER • HEALTHIER • PEOPLE™**

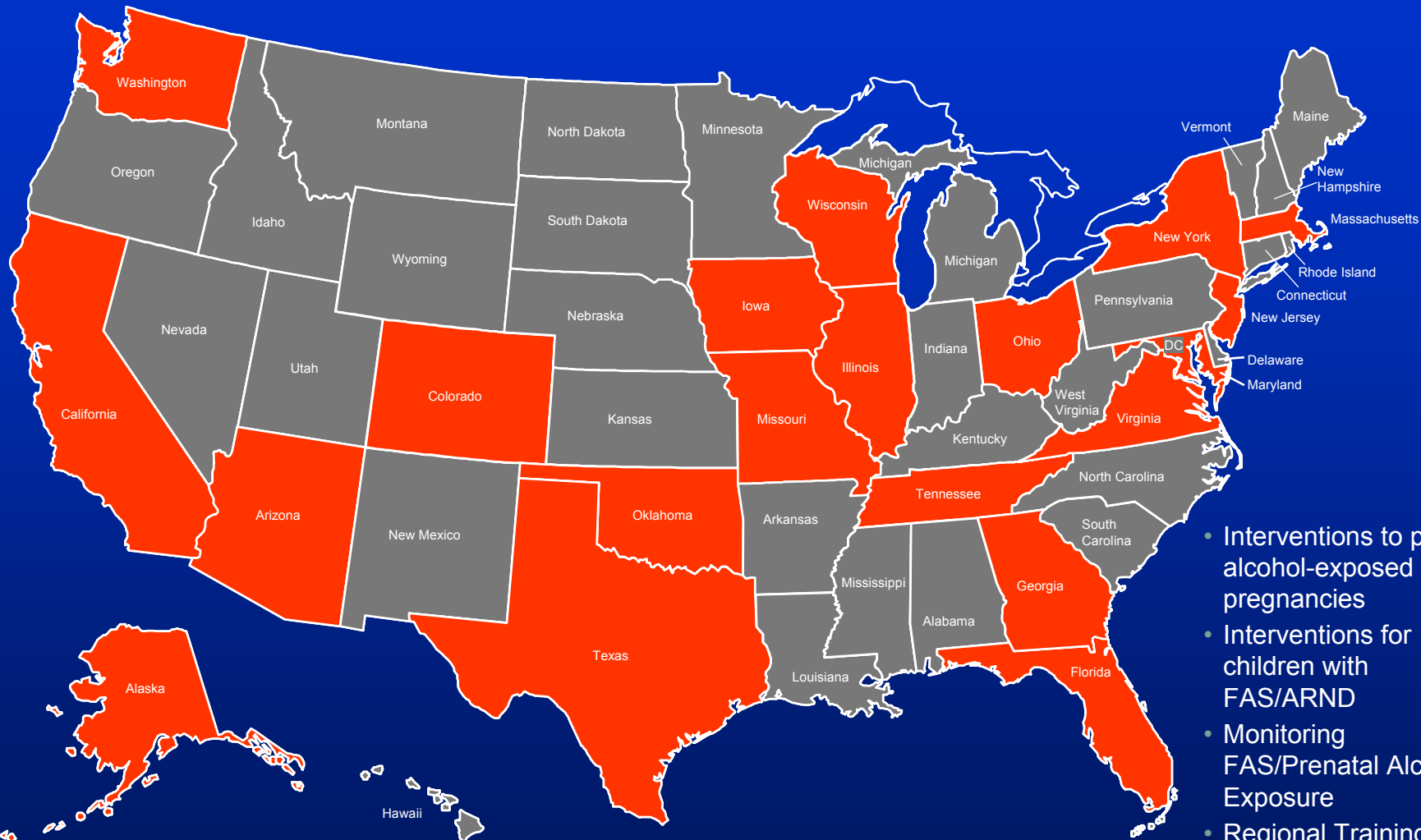
# Follow-Up Study Of Young Adults With Developmental Disabilities

- Completed three projects using a “Multi-Dimensional Approach to the Epidemiology of Developmental Disabilities”
  - 1) Characteristics and factors associated with activity limitations in young adults with childhood impairment
  - 2) Characteristics and factors association with participation restrictions among young adults with childhood impairment
  - 3) Impairment, activity limitations, and contextual factors as predictors of participation restrictions in young adults with childhood impairment
- Completed a study entitled: “Long-Term Assessment of a Newborn Metabolic Screening Program Using a Population-Based Approach to Identify Children with Developmental Disabilities”



**SAFER • HEALTHIER • PEOPLE™**

# CDC Funded FAS Projects



- Interventions to prevent alcohol-exposed pregnancies
- Interventions for children with FAS/ARND
- Monitoring FAS/Prenatal Alcohol Exposure
- Regional Training Centers



**SAFER • HEALTHIER • PEOPLE™**



# Fetal Alcohol Syndrome Prevention Program

- Funded 40 cooperative agreements in 21 states
- Published prevalence rates for prenatal alcohol exposure and Fetal Alcohol Syndrome
- Published survey results identifying community based settings with high proportions of women at risk for an alcohol-exposed pregnancy



**SAFER • HEALTHIER • PEOPLE™**

# Fetal Alcohol Syndrome Prevention Program

- Completed a successful intervention study for reducing alcohol-exposed pregnancies in high risk women
- Began a multisite clinical study to identify evidence-based intervention for improving outcomes of children with FAS



**SAFER • HEALTHIER • PEOPLE™**

# Fetal Alcohol Syndrome Prevention Program

- Launched two Targeted Media Campaigns aimed at reducing alcohol-exposed pregnancies in California and Missouri
- Began two educational intervention studies to reduce alcohol-exposed pregnancies in Hispanic women
- Established a Scientific Working Group to develop uniform diagnostic guidelines for FAS



**SAFER • HEALTHIER • PEOPLE™**

# Fetal Alcohol Syndrome Prevention Program

- Established a Scientific Working Group to develop uniform diagnostic guidelines for FAS
- Funded four FAS Regional Training Centers throughout the country
- Continued support of the National Task Force on FAS/FAE
- Completed the development of FASSNET
- New RFA to be released soon
  - Focus in using surveillance information for the development of FAS prevention programs



**SAFER • HEALTHIER • PEOPLE™**

# Impact of Folic Acid Supplementation and Fortification

- Convened “expert meeting” Feb 2002 to evaluate fortification issues
- Evaluation of intervention in HMO settings
- Evaluation of folic acid supplementation in GA family planning clinics
- Pre-vs. post-fortification monitoring of adverse pregnancy outcomes in HMO population
- Ongoing monitoring of blood folates in HMO population



# Impact of Folic Acid Supplementation and Fortification

- Demonstration projects in Latino community
- Collaboration with March of Dimes
- Distribution of educational materials:  
1.8 million in 1992
- PAHO collaboration and global efforts



**SAFER • HEALTHIER • PEOPLE™**

# Some Thoughts for the Future

- Identify and evaluate strategies to reduce the impact of maternal diabetes on the risk of birth defects
- Preventing adverse fetal effects from medication use during pregnancy
- Continue to study exposures and risk factors for BD and DD
- Use of biologic markers in BD and DD research
- Maximizing the prevention potential of our research findings
- Impact of gene and environment interaction on outcomes



# Some Thoughts for the Future

- Small area analysis to better target and evaluate our prevention efforts
- Developmental screening for early intervention and improved outcomes
- Improving coordination of prevention activities
- Closer collaboration with state and local MCH programs, professional organizations, and our constituency groups
- Capacity development in BD and DD epidemiology



**SAFER • HEALTHIER • PEOPLE™**